DOCUMENT RESUME

ED 370 308 EC 303 040

TITLE	Assessing Health Services Delivery for Children with Special Health Care Needs (CSHCN) in School.
INSTITUTION	Children's Hospital, New Orleans, LA.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Bureau of Maternal and Child Health and Resources Development.
PUB DATE	93
CONTRACT	MCJ-22507
NOTE	7p.; For related documents, see ED 367 125-126.
AVAILABLE FROM	The National MCH Resource Center, Children's Hospital, 200 Henry Clay Avenue, New Orleans, LA 70118.
PUB TYPE	Collected Works - Serials (022) -- Reports - Research/Technical (143)
JOURNAL CIT	Networks: A Newsletter of the National MCH Center at Children's Hospital; v4 n1 Spr 1993
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Access to Education; Delivery Systems; Educational Needs; Elementary Secondary Education; Evaluation; Incidence; Individualized Education Programs; *Information Needs; Information Utilization; *Needs Assessment; *School Health Services; School Nurses; *Special Health Problems; State Surveys; Student Participation
IDENTIFIERS	Louisiana

ABSTRACT

Children and youth with special health care needs frequently require health care during the school day. School evaluations and Individual Educational Plans should include health information addressing students' daily health and emergency needs, should assure services in a setting that is academically appropriate and in the least restrictive environment, and should include goals and objectives to help the student become more involved and independent in his/her own health care. A survey, with responses from 89 percent of Louisiana's school districts, determined that 756 students required selected procedures in school. A study was then conducted with families of 59 of these students, analyzing data from school records of students with special health conditions and assessing students' ability to access health services in order to participate in school. The study found that: health records and official education documents do not contain health information on children with health conditions in school, school personnel who provide health services require additional training, and documentation that would help to ensure safe and adequate service delivery is often missing. Nine recommendations are offered for improving services through collaboration of parents, teachers, paraprofessionals, school nurses, the health care team, and primary care physicians. (JDD)

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ED 370 308

THE · NETWORKS

A NEWSLETTER OF THE NATIONAL MCH CENTER AT CHILDREN'S HOSPITAL

Vol. 4, No. 1 SPECIAL EDITION Spring 1993

Assessing Health Services Delivery for Children with Special Health Care Needs (CSHCN) in School

CSHCN programs are charged with the responsibility of "playing a leadership role in the development of community-based service systems for CSHCN and their families" (MCH Block Grant Systems Development Mandate, 1990).

Educational services are only one component of a service delivery system. The opportunity for collaboration between CSHCN programs and State Departments of Education is essential in developing this system.

This **special edition** of *The Networks* newsletter will focus on a statewide study conducted by the National MCH Resource Center for Ensuring Adequate Preparation of Providers of Care. The goal of this study was to collect data regarding health information included in the school records of students with special health conditions and to assess the students' ability to access health services in order to participate in school. We hope it will provide you with insight as to the quality of health services children with special needs are receiving in school and the barriers that will need to be resolved in an effort to enhance quality services for this population.

Supported by project #MCJ-22507 from the Maternal and Child Health Bureau (Title V, Social Security Act) Health Resources and Services Administration, Department of Health and Human Resources.

Introduction

Children and youth with special health conditions frequently require health care during the school day. Health care needs may involve the management of ventilators, oxygen condensers or other medical devices as well as the provision of procedures such as catheterization, gastrostomy feedings and suctioning.

Problem

In order for students with special health conditions to access safe and relevant educational opportunities, school evaluations and Individual Educational Plans *(IEPs)* must include health information. Personnel associated with the Ventilator Assisted Care Program and the Chronic Illness Program, as well as consortiums of families, health providers and educators, have observed that the majority of school evaluations and IEPs completed for children with special health conditions do not contain health information.

Health personnel can provide important information in the multidisciplinary evaluation by assessing the impact of a health condition on the students' ability to function and learn in school. IEPs should address students' daily health and emergency needs. The IEP should also assure services in a setting that is academ-

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should also assure services in a setting that is academically appropriate and in the least restrictive environment. Finally, the IEP or school health plan should include goals and objectives to help the student become more involved and independent in his/her own health care.

Study Objectives

The objectives of this statewide study were to:

1) Assess the amount and type of health information included in the IEP, School Health Records and School Evaluations of students with special health needs.
2) Assess services received by students with special health needs in the school setting.

Methodology

Initially, all Louisiana parish *(county)* level education districts were surveyed to determine the number of students who required specific health-related services during the school day. This survey was based on school health procedures originally described by the California State Department of Special Education. Eighty-nine percent *(89%)* of the school districts responded reporting 756 students who required selected procedures in school.

A multidisciplinary committee consisting of university-based research specialists, parents, nurses, educators, a psychologist and a state health administrative consultant was formed. This multidisciplinary committee developed the content for the study instruments.

The process of recruiting study participants was complex. Initially, school superintendents were contacted to solicit their permission and involvement in the study. Some school systems required their attorney's approval and adherence to system policies regarding research. For purposes of confidentiality, school superintendents who agreed to participate were asked to distribute parental consent forms. In larger school systems, this often required contact of more than 100 parents. Eventually, 59 families gave consent and agreed to participate in the study. From this study population, five parents and their children participated in a more indepth interview utilizing the parent/student interview protocol.

A nurse and an educator were recruited and trained to collect data utilizing the newly developed instruments. Information was collected as a result of school visits and telephone interviews with families, teachers, school nurses, and paraprofessionals in 23 different school parishes.

Selected Observations

The following observations were reported by the data collectors.

- Communication among families, health and education personnel was often lacking.
- Health information was often not accessible to school and education personnel. When accessible, the information was often not timely or relevant.
- The term "health records" was not consistent across school districts. Information included in "health records" and the location of those records varied greatly.
- Some parents were not familiar with the range of related services for which their child might be eligible.
- IEPs seldom identified personnel responsible for providing health related procedures in school.
- School nurse involvement in the IEP process was inconsistent across school parishes. Job descriptions and definitions of nursing responsibilities varied across school parishes.
- Many school nurses expressed concern regarding the following:
  - *students unidentified to them who were in their jurisdiction and receiving health services*
  - *the quantity of students for whom they were responsible*
  - *the large geographic areas for which they were responsible*
  - *their responsibility for supervision of nonlicensed health care providers in school*
  - *the lack of access to current information regarding students and their health needs.*
  - *the lack of access to opportunities for clinical skills training*
  - *the lack of involvement in the evaluation, placement, and development of a student's IEP*

Selected Results

A vast amount of information was collected. A small selection of the data that was collected is presented in the following three (3) tables.

Table 1 describes the documentation of health information in the appropriate school records of students with special health needs.

Description of Student's Health Needs Reported by Form Reviewed? (Percentage of "Yes" responses)				
	IEP	Health Records	Evaluation	Total
General health information is stated	82.4	81.5	95.6	86.60
A primary medical diagnosis is stated	72.5	81.5	91.8	81.93
Related conditions are stated	88.2	81.5	91.8	87.17
Precautions related to primary diagnosis are stated directly	13.7	42.6	14.3	23.53
Warning signs and/or symptoms are stated directly	2.0	22.2	8.2	10.80
Signs of immediate danger are stated directly	3.7	38.9	22.4	25.00
Scheduled treatments are stated directly	54.9	66.7	55.1	58.90
Other treatments are stated directly	17.6	27.8	14.3	19.90
Medications are stated directly	25.5	48.1	49.0	40.87
Possible side effects of prescribed medications are stated directly	2.0	14.8	8.2	8.33
Special nutritional and/or fluid needs are stated directly	45.1	46.3	34.7	42.03
Special equipment and/or supplies are stated directly	80.4	72.2	71.4	74.67

Table 2 provides information on training issues as an indicator of quality of service delivery.

WHAT KINDS OF HEALTH RELATED TRAINING DID YOU RECEIVE? Perecentage of "Yes" responses for cases where the school nurse is the primary service provider of health needs (N=21)			
Training	School Based Training	Non-School Based Training	Was it Adequate?
CPR	57.1	76.2	100.0
General Orientation	57.1	66.7	95.2
Diagnosis Specific	38.1	47.6	76.2
Child Specific	76.2	28.6	76.2
Hands-On Practice	76.2	47.6	95.2
Warning Signs/Symptoms	57.1	57.1	90.5
Emergency Procedures	57.1	52.4	81.0
Training Updates	42.9	52.4	61.9

Table 3 describes the degree to which children's health needs were met in school as perceived by various caregivers.

Data was collected for 57 cases. One to five individuals responded for each case. Fifty-five (55) parents, 49 school nurses, 27 teachers, 35 aides and four other school employees responded. The average response was quite positive. However, parents were somewhat less positive than other adult caregivers.

RESPONSE						
	Extremely Well				Not At All	
Frequency	1	2	3	4	5	Total
Parent	30	11	6	3	5	55
	54.5%	20.0%	10.9%	5.5%	9.1%	
Nurse	35	9	2	3	0	49
	71.4%	18.4%	4.1%	6.1%	0.0%	
Teacher	27	4	2	1	0	27
	77.1%	14.8%	7.4%	3.7%	0.0%	
Aide	27	7	1	0	0	35
	77.1%	20.0%	2.9%	0.0%	0.0%	
Other	4	0	0	0	0	4
	100.0%	0.0%	0.0%	0.0%	0.0%	

- **54.5%** of the parents attributed the reason for satisfaction of the service to: *a)* efforts of school personnel and *b)* efforts of the mother.
- **70%** of nurses, teachers and paraprofessionals credited *open communication* between home and school as the main contributor to level of satisfaction.
- **45.5%** of parents cited the following categories as suggestions for improvement in health services: additional school personnel, increased sensitivity, increased knowledge, improved communication and additional funding.
- Nurses, teachers and paraprofessionals cited the lack of adequate personnel as a deterrent to providing adequate health services in school.

Recommendations

1. Written procedures should be developed outlining the steps involved in providing health services for children with health conditions. These procedures should also indicate the person responsible for implementing each step. It would be useful to have these steps available to the parents in order for them to anticipate the next step.

2. The school nurse should be involved in the initial identification of the child. He/she should conduct and write a nursing assessment on each child in his/her jurisdiction. The school nurse should be actively involved in the evaluation, IEP, and placement of a child with a special health needs.

3. If the nurse is delegating a health procedure to a nonlicensed care provider, he/she should be involved in the training. Additionally, a system for supervising, monitoring and updating the skill level of these care providers should be developed and updated at least annually.

4. There must be documentation of all aspects of a child's health needs. These records should be consistently placed and easily accessible to all caregivers. Information should include:

1. *Primary medical diagnosis*
2. *Related conditions*
3. *Warning signs and/or symptoms*
4. *Signs of immediate danger*
5. *Precautions related to the health condition*
6. *Scheduled treatments*
7. *Medications*
8. *Possible side effects of prescribed medications*
9. *Special nutritional and/or fluid needs*
10. *Special equipment and/or supplies*

FOR MORE SPECIFIC INFORMATION, refer to the *Community Provider's Guide: An Information Outline for Working with Children with Special Health Needs*

5. Procedures should be documented at the time they are performed.

6. Lines of communication should be established between all caregivers (parents, teachers, paraprofessionals, school nurses, the health care team and primary care physicians).

7. Minimum competencies should be required for all health providers in school. These competencies should include:

a. *CPR - current certification*
b. *Universal precautions*
c. *General review of body mechanics*
d. *Psychological issues*
e. *Procedure specific training*
f. *Child specific training (to include warning signs and symptoms and emergency protocol for each child)*
g. *communication/exchange of information*

FOR MORE SPECIFIC INFORMATION, refer to the *Community Provider's Guide: An Information Outline for Working with Children with Special Health Needs, 1991 Addendum*

8. Parents and school personnel should encourage documentation of Health Services on the IEP. Health Services can be considered a related service for which a child is entitled. The IEP should contain goals and objectives towards which the child should strive in an effort to achieve full potential in self-help activities.

9. Children who are in regular education and do not have an IEP should have an IHCP (Individual Health Care Plan). An IHCP should include all the health information listed in Number 4 as well as goals for achieving full potential in self-care activities.

Conclusion

This study reinforces what parents and professionals have been voicing for some time. First of all, health records and official education documents do not contain health information on children with health conditions in school. Secondly, school personnel who provide health services require additional training in order to meet the health needs of these students. Finally, documentation that would help to ensure safe and adequate service delivery is often missing. The study indicates that parents, education and health providers should work collaboratively to develop systems which will ensure the safe provision of health services for children. ❖

Bulletin Board

The Bulletin Board is an electronic forum where users have instant access to a variety of resources and information. Features of the system include:

- Posting of latest conferences and seminars.
- Messaging services whereby users can post mail to one another.
- National conferences area where users can join in on discussions with other users and request information on specific topics.
- Database searches of local, regional and national resources and organizations.
- Database searches of the National Center's library and resource lists.
- Selected current articles available for browsing and downloading (transfer to the user's computer).

The bulletin board can be accessed by any personal computer with a modem and communications software at ***(504) 897-9204***. For information or assistance, call the systems operator at ***(504) 896-9287***.

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